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ABSTRACT

This newsletter issue focuses on ways parents can manage the difficult child with special needs. Characteristics of the difficult child are listed including poor listening skills, irritableness, impulsivity, and tendency to have tantrums. Typical reactions to the difficult child by parents, siblings, other relatives, neighbors, the school, and peers are then noted. An observation period in which all behaviors are documented is recommended. Suggestions for changing undesirable behaviors include building structure into family routines, modifying the home setting to meet the child's needs, and setting some easy-to-follow consistent rules. Finally, do's and don't's include "do use alternative methods" and "don't bring up past misbehaviors". In addition to the main article, the issue contains two shorter articles: (1) "Parent-to-Parent Network: Fragile X Syndrome--in my Family?" (Alicia Campbell); and (2) "Dealing with Childhood Temper Tantrums" (George Popper). (DB)

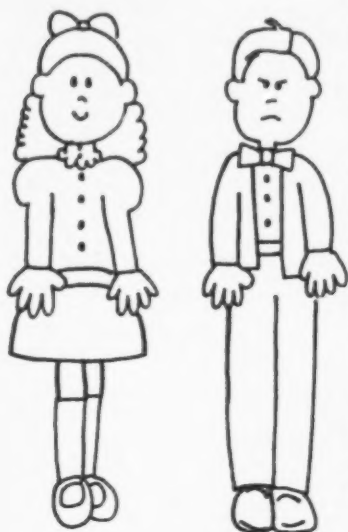
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Special Parent ★ Special Child ★

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MANAGING THE DIFFICULT CHILD



Some children are born more difficult to manage than others. Most mothers can confirm this commonsense observation, pointing out vast differences in temperament and behavior between siblings, even as infants. It has taken researchers until recently, however, to document what every parent knows! Current theory corroborates that some children, for whatever reason, are in fact born more susceptible to environmental stress (noise, hunger, fatigue) and are in general highly irritable, sensitive and definitely harder to manage.

What is even more characteristic is that for many children *the picture does not change*. Hapless parents who wait for their difficult children to "outgrow" their unfortunate tendencies find themselves thwarted and frustrated at every turn.

Special children, perhaps because of their overall sensitive nervous system, are specially prone to hard-to-manage traits, presenting an even greater challenge to their parents.

In this issue we will focus on recognizing those aspects of your child's temperament that make her more difficult to raise and how to manage these traits more effectively so that each member of the family has the opportunity to enjoy family life.

Recognizing the difficult child's traits

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Linda Murphy

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

Many difficult children display such a confusing welter of misbehaviors that parents throw up their hands, describing their errant child as "bad," "wild" or "naughty." In order to remedy the situation, however, it is best to be able to have a definite picture of what actually occurs. Perhaps your child's teacher, or the child's grandparent or your spouse can help you draw up a list of what typifies your child.

Look for the following characteristics in your youngster:

- doesn't listen
- often cranky or irritable for no reason
- distractible, can't sit still
- bothered by heat, cold, hunger, fatigue
- reacts poorly to noise, crowds, lights
- high activity level
- can't focus for any length of time
- highly impulsive, unpredictable
- whines, cries easily

- reacts badly to changes in routine
- sleeps or eats poorly
- wants her own way
- won't share, doesn't play
- often moody or sullen
- manipulative
- stubborn, rules the roost
- has frequent unwarranted or extreme tantrums.

If your child has more than five of these traits and has had most of

them from infancy, she can be classified as difficult. Children who persistently exhibit these displays of temperament are a puzzling trial to all. Most parents find themselves bewildered from the continual pressure of having to constantly monitor their child's every waking hour. As one exhausted parent commented ruefully, "I don't have a minute's peace to myself."

Reactions to the difficult child



The child who exhibits difficult behavior has an impact not only on the entire family but on all who come in contact with her.

Husband and wife. The stress between husband and wife can become extreme. Marital discord occurs especially if the husband and wife blame each other, or have frequent disagreements over how best to manage their child's behavior consistently.

Siblings. Problems arise with siblings who feel less attention is paid to them and that their needs are pushed aside. Their complaints are frequently justified, and parents often have to perform juggling acts in order to meet everyone's needs.

In-laws, relatives. While in-laws and relatives can be sympathetic, they too are often taxed by the difficult child's unmanageability. Relatives who make thoughtless comments about your lack of parenting skills, or who make it clear that "this didn't come from my side of the family" can add to the generalized woe.

Neighbors. By the same token, neighbors who observe your

child's misbehaviors or hear the tantrums are often unintentionally cruel, especially if they speculate about your fitness as parents.

It is very hard to explain your child's difficulties to friends and neighbors when you have a hard time explaining them to yourself!

School. It is axiomatic that difficult children will have serious school-related problems. Their poor impulse control and difficulty in sitting still, paying attention or completing tasks invariably interfere with academic achievement.

Peers. The saddest fact of all is that the difficult child's temperament is a deterrent to making or keeping friends. The child's impulsivity and lack of awareness of social cues are manifested by an inability to share toys, take turns or partake of friendly interchanges.

Thus the world at large looks askance at the social behaviors of the hard-to-manage child. Families tend to isolate themselves, remaining in the confines of their own homes where the vexing behaviors of their difficult child can be hidden from raised eyebrows and caustic comments of others.

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Evaluating the situation

The best way of dealing with your child's offensive behaviors is to step back and make a careful, realistic appraisal of exactly when and where the offensive behaviors arise. Random or haphazard efforts to change your child's behaviors will not be as effective as a well-thought-out plan based on careful observation.

Ideally, **the observation period** should be one week long and include the weekend. Observe how your child's temperament varies from day to day and in a variety of settings. Note carefully, for example, how she behaves early in the morning or late at night, reacts to food intake, copes with fatigue. Find out if there are certain times when the offending behaviors occur more frequently than others. Take particular note if the child is more relaxed on weekends. Note if there are differences in behavior

when your child is in crowded rooms, or with other people around, or when it's noisy.

Make a list of all behaviors. Include any appropriate behaviors you have observed as well as those that are troublesome. Study the list carefully and ask yourself what your typical reactions are. Do you, for example, make no mention of appropriate behavior and only pay heed when the behaviors are out of hand? Do you raise your voice, scream, punish, or threaten for all or just some transgressions? On the other hand, do you tolerate extreme behaviors until others react or step in?

Once you have classified which behaviors upset you or other family members the most and once you have determined when and where they occur, you can then realistically design ways of changing the situation.

Changing the behaviors



Families should recognize that it will take everyone's cooperative efforts to remedy the situation, especially when patterns of behavior are long-standing. Here are some practical strategies that should help.

Build structure into family routine. Hard-to-manage children need to know what is expected of them. Your child's daily routine should follow a predictable, consistent sequence—regularly-scheduled mealtimes, TV times, bath times, bed times. The difficult child needs concrete reminders of what comes next: for example, "After dinner you may watch TV for one hour, then there is bath time, then bed." Any change in routine should be explained as simply as possible, for example, "When Grandma comes, dinner will be later, after TV time."

Modify the home setting to meet your child's needs. Your home should be as relaxed and tension-free as possible. Go back to the observation list you have made about when and where your child functions best. If noise makes her out of sorts, or if she is excessively irritable when tired, modify the family routine to take this into account. Don't, for example, expect the child who is particularly out-of-sorts in the late afternoon to feed the dog, set the table and finish her homework at that particular time.

Set some easy-to-follow consistent rules. Both parents should discuss this beforehand, making sure they agree on what rules are to be followed. These should be discussed with the entire family and *all* children should be expected to follow them. Conse-

quences for breaking rules should be clearly stated, firmly but positively. For example, explain that running away from the table at mealtime is *unpleasant for everyone* and that therefore jumping up at mealtime will result in the plate of food being removed. Make sure your children understand what is expected of them and, above all, be consistent. Setting limits one day and making allowances the next is not only confusing but will tempt your child to test the rules you have made.

Start off with rules that are easy to comply with, so the family feels they can function successfully.

Consequences for breaking any of the agreed-upon rules should "fit the crime." In order to have maximum effect, rules should be fair, and consequences for minor transgressions should never be excessive.

Build a system of rewards.

Some parents are convinced that the only way to influence a child's behavior is by punishment. Unfortunately, this method backfires. First, punishment does not show the recalcitrant child an alternative, positive way of behaving; so she continues to misbehave, mostly because that's all she knows how to do. Secondly, most parents become so guilty about having to punish their child that they either

ignore the child's misbehaviors or punish them excessively.

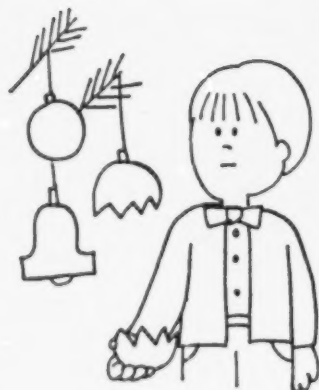
The most effective method for encouraging good behavior is the use of rewards. Rewards can be explained as a token or payment for good work, in much the same way as an adult's "good work" is "rewarded" with wages.

The reward system should be planned in advance and should be meted out for a specific, stated behavior, not simply for being "a good girl." The reward itself should be something tangible and should be given out immediately.

Choose a troubling behavior or habit that is fairly easy to change. For example, your child should be given a small trinket or desirable, inexpensive object if she complies with riding in the car without protest. In this way your child can build on a sense that she is a productive, successful family member.

Even though it is not always possible to erase all the hard-to-manage child's difficulties, accentuating the positive is a better way of going about things than dwelling on what is wrong.

Once you have defined the problems, designed a system of dealing with them and made some efforts to provide a structured, nurturing environment, you can be assured your child is being given the best opportunity to thrive.



Do's and don'ts

Do remember that holidays are overstimulating for everybody. All children react to the heightened excitement of the holiday season and can become cranky and overtired with the change in routine, late nights and extra visits. Your difficult child is especially vulnerable, so schedule quiet times, if at all possible.

Don't overload your child's susceptibility to environmental noise and confusion by long, tiring shopping expeditions to crowded malls. Go before the crowds and find parking close to an exit. Plan your shopping carefully; know exactly where you are going. Avoid browsing as this is likely to be boring and confusing to your youngster. Leave the mall early *before trouble starts*, and reward



your child with a treat for her good behavior.

Don't barrage your child with complicated verbal explanations or directions. Most special children find non-stop commentaries overwhelming and their inability to follow your requests may reflect confusion rather than willfulness.

Do resist the temptation to lash out at your child physically. Although this does not rule out a firm tap, especially when moving your child out of harm's way, it does mean that physical handling often escalates to loss of control and can result in abuse.

Do use alternative methods. Sometimes acting out scenarios with the use of puppets or drawing pictures shows your difficult child how her misbehavior effects others.

Do remember that one of the most effective methods of control is to remove your child from the scene. Designate a "quiet area" in your house where your youngster has no toys, TV or other diversions and where she must remain for a short period of time until she is ready to act appropriately.

Don't bring up past misbehaviors or rage about yesterday's misdemeanors. Each day should be treated as an opportunity to make a fresh start. Your youngster should feel that each day contains an incentive to act positively.

Do be a good role model yourself. Losing your temper, screaming, yelling, crying and other losses of control can frighten the difficult child to the extent that her misbehaviors escalate rather than diminish.

Don't lose heart when things don't immediately change for the better, no matter how carefully you've carried out your strategies. Remember, it took a long time for the misbehaviors to become implanted. Even under the best circumstances your difficult child is going to remain a constant challenge. The best thing to do is to choose a plan the family feels the most comfortable with and *stick to it*. Sometimes it takes a very long time for it to sink in that this is the way the family is going to function from now on.

PARENT-TO-PARENT NETWORK: Fragile X Syndrome—in my family?

Reprinted from the *American Speech and Hearing Association Journal*, September 1990, "Consumer Corner," with permission of the American Speech and Hearing Association.

Alicia Campbell, president of the Mid-Atlantic Fragile X Association, has two children with Fragile X (fra X) syndrome, Paul, 10, and Laura, 6. During a recent interview, Campbell discussed the impact of fra X on her family.

What led to the diagnosis of fra X syndrome for your son?

You exhaust yourself trying to find a diagnosis. For years my address was "Interstate 270, my automobile," traveling to find a diagnosis and receive treatment. Paul was five years old before fra X syndrome was diagnosed. Before

that, we attributed his developmental delays to early medical problems. Paul was born with a bilateral hernia and had surgery at three months. Paul was a very vocal child—at six months he repeatedly made high-pitched sounds and babbled a lot. However, the babbling didn't change to real words.

We consulted the first professional, an audiologist, when Paul was 18 months. Paul's hearing was normal, so we went for a speech and language evaluation. Paul showed a six-month delay, but this seemed consistent for a



child who'd had surgery. However, the speech-language pathologist noted perseveration in his speech and recommended treatment.

A psychological evaluation was next. It didn't indicate any significant delays. We started speech-language treatment and nursery school when Paul turned three.

In addition to delays in speech and language, Paul started biting his sleeve. This behavior coincided with his sister's birth so we attributed it to stress and change in the environment. When Paul was four years old, he started hand-flapping and this became more pronounced. He also had repetitive speech and motor movements. Even his drawings were always the same—faces with uncentered eyes. A second psychological evaluation was done and Paul was diagnosed as having sensory integration dysfunction.

When Paul was five years old, we enrolled him in a private school for children with developmental delays. The director and assistant director suggested Paul have genetic testing for fra X and this confirmed that Paul did have the syndrome.

Were you relieved to have a diagnosis to explain your son's delays?

No and yes. No, because I couldn't accept it. This couldn't happen in my family. All my nieces and nephews are exceptional students and very talented. How could there be mental retardation in this family? Paul didn't look very different. He had some of the common physical features—large head (big brain, we called it) and one of his ears stuck out. But we had his ears surgically corrected. He also had poor vision and allergies.

Yes, because it was a relief to know that it wasn't anything I did wrong during pregnancy and I finally had a diagnosis.

What was the impact on your family?

It had a tremendous emotional impact. We went through all the stages of grieving. At first, we mourned the loss of our expectations and ambitions. Paul's needs put a strain on our marriage. I couldn't have a better husband, though. When the stress is very bad we co-exist. All I can deal with sometimes is myself and my children. Many people have more than two children with fra X syndrome.

It was very painful for our whole family. My mother aged ten years because of her suffering for me. Can you imagine what my mother was feeling? My mother's fear was that it was her fault for passing the gene to me. As a result, she was grieving for her daughter and grandchild.

It's also tough on my in-laws who live out of town. They come to visit for a week and are faced with all sorts of restrictions because we need to maintain a structured family routine. Paul gets overstimulated when his routine is disrupted. However, now that he's older, he can handle more changes and stimulation.

I gave up my career as an elementary school teacher and stopped a PhD program. My husband left his government job and commuted to another city for a higher paying job. He returned to the government job later because it offered better insurance coverage, and eliminated the considerable amount of travel away from home. Also, can you imagine losing your son (through the diagnosis) and your husband (due to traveling) at the same time?

Did you have any difficulty finding educational services for your son?

We had to sue our county and the state. After spending three years and tens of thousands of dollars, we lost due to procedural irregularities by the state. We decided to move and Paul now receives excellent services in a private school, which are paid for by the county.

What is special about this school?

The school has a terrific staff of caring professionals who believe, as I do, that Paul can learn. They don't just look at his weaknesses; they recognize his strengths and moments of brilliance. He needs an individualized program de-

signed for his special needs. At Paul's school there is complete cooperation among the speech-language pathologists, occupational therapists, social worker and classroom teacher.

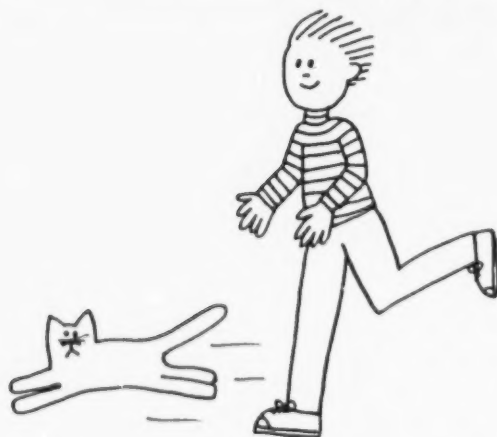
What kind of help does your daughter receive?

Laura will be attending regular school although she will be placed in special education. She will be in a small class with speech-language treatment, sensory integration occupational therapy and physical therapy. Also, she will be mainstreamed. She may need help with math.

We still felt a loss when she was diagnosed with fra X syndrome, but it's easier with her because the prognosis is good and she has above average intelligence.

What has helped you to cope?

Talking to other parents is the biggest help. Parents hear a lot about the genetics of fra X syndrome but that doesn't help us provide educational and other services for our children. I believe that with early diagnosis and interdisciplinary treatment, children with fra X syndrome will learn and will be productive members of society.



PSYCHOLOGIST'S CORNER

Dealing with childhood temper tantrums

by George Popper, Ph. D.

Occasional childhood temper tantrums are a normal part of growing up. Some psychologists regard these outbursts as instinctual, natural expressions of aggression and rage; they are the child's way of letting you know that he is angry. As language skills develop and children are able to verbalize what they want, the diffuse, non-directed rage seen in very young children becomes less acute. Unfortunately, for the special child who has language delays, the problem can persist and become more severe.

Social aspects. Children learn what they live. If a child grows up in a home with verbal or physical aggressiveness, there is a good chance he will imitate what he sees and hears. If the child perceives that aggressiveness is rewarded, he will learn to act out verbally and even physically. There is also a good possibility that the violence seen on television may be duplicated by young viewers. Thus, children learn at an early age that violence and rage are useful tactics when you want to get your way.



Behavioral aspects. Frustration in varied forms contributes to a child's ability to handle and express anger. For the special child frustrations are an everyday occurrence. Simple motor tasks, reading, solving math problems, making friends, playing games or even tying shoe laces become defeating, thwarting obstacles for many special children rather than challenges to be conquered. Special children want to succeed, but when they can't, what's left is anger and rage.

Parents can help their special children control their behavior by helping them to gain a feeling of some control over their world. It is tempting for a parent to step in and hasten the sometimes painfully slow process of buttoning a shirt or zipping a coat. However, the more independent a child becomes, the greater the likelihood he will not act out when the parent is not around to help him or finally decides to encourage him to do things on his own.

Parents, teachers and others can feel frightened, overwhelmed and embarrassed by the tantruming child. Consequently, parents find that much of their time is devoted to bowing to their child's demands in order to forestall embarrassing outbursts. Even other siblings are admonished to give in to their special brother or sister so they won't become "upset." It is easy to imagine how quickly the special child learns the value of a violent outburst.

What about the common idea that "ignoring" the tantrum will eventually make it stop? In all probability, the child will persist and parental efforts not to respond to the tantrum may only seem to increase its intensity and duration. Parents who fail to understand that they are being tested may be inclined to believe that ignoring the

tantrum is not working. As a result, they give in to their child's demands, believing this is the easiest approach to take. Unfortunately, they don't realize that their inconsistency has only strengthened their child's resolve!

In order to feel safe and secure children need to know that their parents are in control. This means that tantrums, although a part of growing up, need to be addressed from the beginning. Parents need not feel helpless; there are many positive ways to teach children less destructive expressions of their anger. Here's how:

1. Be a good role model. When children see their parents act out verbally or physically, they will imitate their behavior.

2. Encourage your children to be as independent and self-sufficient as possible. This will require a great deal of patience and perseverance on your part, but it's worth it in the long run. Children who develop a sense of competence don't need to act out.

3. Teach your children how to express feelings of anger and frustration in ways that are not self-destructive. Let your child know that it's natural to become angry and frustrated and that you understand what he is going through.

4. Make sure that your child's tantrums will result in a loss of attention while appropriate reactions bring the very attention the child is seeking.

5. Occasionally, tantrums may indicate hyperactivity or Attention Deficit Disorder (ADD), requiring a clear diagnosis. Nevertheless, the social and behavioral aspects are always important, no matter what the underlying cause. Needless to say, professional help should be sought if the problem is severe.

Illustrations by Leah Spring

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Linda Murphy, M.S., is the founder and for the past 15 years has been the director of a widely known, approved school for mentally handicapped children serving children ages 5-21 in Westchester County, NY, and surrounding areas. A lecturer, teacher and administrator, she is a foster parent and the parent of a handicapped child, too.

Suzanne Della Corte, M.S., for 15 years co-director of the school, is responsible for curricula, staff development and supervision. She is author of numerous research projects in the field and has edited psychology textbooks for a leading New York publisher.